

## Day 2

### Get on board

#### **Board of Health Consumers Queensland**

- **Mark Tucker-Evans, Chair**
- **Dr Erin Evans, Director**
- **Stephen Russell, Director**
- **Rachelle Foreman, Director**
- **Gabrielle Quilliam, Director**

**Mark Tucker-Evans:** Thank you everybody for sticking around. We appreciate it has been a long two days, but we certainly appreciate you being here. Before we start this session, I'd just like to acknowledge Melissa and her team with a special mention of Chelsea and also Michael or anybody who was in the session in here before morning tea, as he will forever now be known as "the brother with the hair", so thank you Robbie for that description. (APPLAUSE) I'm sure you'll agree this has been an extraordinary couple of days and really on behalf of the board I'd like to thank our team, but also all of you because without you it wouldn't have been the event that it has been. So thank you and I'll do some formal thanks at the end of this session. Yesterday I promised that you'd have the opportunity to meet the Health Consumers Queensland board and hopefully you've been able to do that individually over the last couple of days, but this is the opportunity to actually meet us collectively and to ask some questions. But before I do that I'll facilitate a conversation with my fellow directors to get each of them to share why they've put themselves forward to govern our organisation and what led them to become passionate advocates for consumer engagement in the health system. I've actually had the privilege of leading Health Consumers Queensland since we were initially established as a ministerial advisory council in September 2008 following the Patel incident in Bundaberg in 2005.

Initially, we actually started as a 12-person ministerial advisory council and I'd like to acknowledge Janelle and Odette and Melissa Fox who were members of that 12-person

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advisory council and those three are in the room today. So, it's been an interesting and somewhat sobering to be reminded that that was ten years ago in a few months' time. In some ways the time has flown by, and in other times it hasn't. We're also fortunate today to actually have our inaugural director Paige Armstrong give the first plenary session and Paige is now the chief executive of Queenslanders with Disability Network and it's interesting. We've had other staff of Health Consumers Queensland over the last decade who are here now in other roles, as well. So it has been a great journey and it has certainly been a privilege to be part of that journey. For me, my engagement with the health system actually started when I joined Council on the Ageing in 2001 and previously I'd been in a range of other roles, but it seemed to me that with health being such an important part of growing older, that it seemed strange that there wasn't actually a consumer organisation.

So we actually tried to get a branch of consumers health forum which is the national organisation, established in Queensland and at the time they weren't interested in having branches around the country and they still aren't. There are now health and consumer organisation in pretty much every State and Territory. But we actually became quite active even prior to the Patel incident, but it really then ramped up. So it was an honour I guess to be chosen by minister Stephen Robertson as the first chair of Health Consumers Queensland. Someone persuaded me to apply for the job and I was interviewed by people little realising what that would actually lead to. But we've worked now with about half a dozen health ministers and almost as many DGs. I've got to say that part of that experience has been that you do need great leadership from the top. Not all those health ministers have been as committed as others and I'd say the same thing with the Director-Generals, as well. I'm not a government employee. I manage a nongovernment organisation CODA, so it does give me some freedom to actually advocate and not be restricted by being involved with government. But the things that I express today are my own personal views, so I think we're really fortunate at the moment to have the leadership team that we've got within Queensland Health. Michael Walsh the Director-General, John Wakefield who you heard from earlier this morning, the leader of the Clinical Excellence Division Nic Steel who's the deputy Director-General of purchasing and we've been doing some work with both John and Nic around value-based health care, what matters to us as

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consumers. Ten years ago, would we have been so involved? I'd have to say actually yes, because at the time Mick Reed who unfortunately got somewhat floundered out of the water by the payroll dispute or payroll issue, but Nic was I think a great leader. He wasn't a doctor. He came to Queensland Health and he really was passionate about consumer involvement and regularly came to each of the meetings of the ministerial advisory council.

In fact, he came to a meeting the day that the health payroll issue blew up. He felt that it was so important to actually meet with the consumers that he kept that appointment. I had the privilege about eight years ago of being on the selection panel for all of the then inaugural chief executives of the hospital and health systems. So that just demonstrates Nic's value of having consumers involved at that high level. In fact, at one stage I actually had an office on the 19th floor of the building in Charlotte Street not that I got to use it very often, but again I think it demonstrates that with great leadership, consumers can actually have the choice.

My vision for Health Consumers that we co-design the system and if we did... I'm probably biting the hand that feeds me here, but if we did, we actually wouldn't have it funded the way it currently is funded. We wouldn't have the feds and the States fighting over what gets funded we'd be designing what matters to us and that's the excitement that I see in the values-based health system. With those few words about my involvement, I'll now turn to my left and ask Steve first, so what inspired you Steve to become involved in health consumer engagement?

**Stephen Russell:** Thanks, Mark. I started life with a chronic illness that didn't have any specific treatment. I spent most of my or much of my childhood and teen years hospitalised or bedridden. Perhaps the easiest recollection of having alerted to the inequities in the deliveries of health is about the age of 9 or 10 when I was in the Darwin Hospital which was actually just located near Cullen Bay and Cullen Bay also had an Indigenous community and so the majority of patients in the hospital were young Indigenous kids and clearly it became obvious to me that I was well ahead in terms of the opportunities in life. I suppose in my teens I became more an activist than an advocate. I think that was the thing you did in the '70s. There was Vietnam War and there were

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environmental issues and my father was a military officer so we used to take great pleasure I think in opposing each other's views. Early 20s, I saw the need to set up a support group for my particular consumer group which is Bleeding Disorders and from that stage on I became actively involved in advocacy across a whole range of health delivery issues. Not just related to bleeding disorders. Doors opened and life transpired and went on to be an elected representative and took on health portfolios at local government level and subsequent to that, chairs of health consumer organisations and here I am with Health Consumers Queensland. Most honoured to be here. It's certainly a dynamic organisation and we certainly have strong values and something that I really appreciate doing and hopefully make a contribution.

**Mark:** Gabrielle.

**Gabrielle Quilliam:** Hi, my name is Gabrielle Quilliam. I'm the co-founder of Humming bird House, the children's hospice based in Chermside. I'm a nurse and midwife by trade and I worked overseas in humanitarian experiences and I realised as I reflected, why have I engaged in consumer engagement, is that it's always just been a part of my nature and my life and the roles that I've played as a nurse and a midwife have always actually been centred around trying to engage with the person that I'm working with, and the backstory to Humming bird House, we were foster carers and we welcomed a beautiful girl with a life-limiting condition into our family and as we walked that journey we recognised there was a significant gap in services for children with life-limiting conditions and their family and their social networks and with my background with a little bit of knowledge of the health system and my husband with business and IT management background we felt we were probably well placed as carers to start advocating for the other families that we walked alongside. It was back in the day of the Royal Children's Hospital and you're in a 6 to 8-bed ward with the curtains between you and you got to know very quickly that there were so many other stories. Our little story was just a drop in the ocean. We decided that it was actually just too big for us as Paul and Gabrielle and we started to change the idea around going, moving it from an I or an us to a "we", as we started to talk with families we recognised the power of the collective conversation and not only did it create community, but it also created an opportunity for really articulated

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comments around how we could help improve the gap that we were recognising and needing and so we were part of parliamentary inquiries, Senate inquiries.

We received government recommendations, pushed through with government funding and have now delivered Hummingbird House as the children's hospice here in Queensland. The other side of it is during that whole experience, I really learned the very real truth of you're given two ears and one mouth and I really learnt to listen, listen, listen and use my words very carefully when I had the opportunity with a representative who could influence decision-making. That's what I've enjoyed about coming on the board with Health Consumers Queensland is I love listening, because there is so much rich resource that goes beyond my experience and then being able to work with a team to create that articulated focused opportunity using all of our collective ears and the combined mouthpiece of Health Consumers Queensland. It's a real honour and privilege and looking forward to working with so many good people.

>>: It's a great question, and I sort of rolled it back to early family imprinting. My grandfather had MS and so my grandmother was his carer. My grandmother used to - I used to spend a lot of time with her. She was caring for me as well and so I spent a lot of time as a child going in and out of hospitals and health systems and things like that with my grandmother and with my grandfather and so I grew up with a vision that I really wanted to work and do things to make things better for the health system, for people with health conditions and so I went into training in medical research and worked within the health system largely overseas and then an opportunity arose to be able to join the board of Health Consumers Queensland and it brought together some of my strong passions of community advocacy and activism... although we're not quite an activist organisation, but certainly advocacy with my passion for health and making a difference.

**Rachelle Foreman:** Thanks, Mark. I'm Rachelle Foreman, I've been here 6 months and I guess what inspired me to apply was really I have a health professional background. I used to work as a clinical exercise physiologist before they existed and I worked in cancer care with older adults and I knew from a young age, that's when I was in my 20s and I knew I wanted to work with people with chronic conditions to help them through the journey and

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I found early on I, like Gabrielle, had a knack to listen and for people to tell me things that were not really in my scope as an exercise physiologist and even though they'd call me "Madam Lush" they weren't exercising before the cancer diagnosis and they were wondering why they would want to start. We would talk about movement and talking about keeping them active and on and off the toilet and all those sort of things and they told me early on that they felt heard, they felt like they weren't a number, so I guess I had empathy. Since then I've worked in the health system in various guises, now in the public health realm with the Heart Foundation, but taking that advocacy role. In that role like Mark I've had a lot of experience with the system enablers and I felt along with that and discovered when I did my board training nearly ten years ago that I'd actually been on boards since my early 20s, but they just weren't always called boards. I have a passion for good governance and strategic thinking - some people's eyes glaze over at that, but that does float my boat a little bit. I felt the merging of the two was a good opportunity for me to continue to be a passionate advocate for the greater good.

**Mark:** Thank you. The role of the board is really to set the strategic direction for the Health Consumers Queensland. Melissa and her team, and to oversee the work of our organisation. We don't get involved in the day-to-day work as directors. So we are a governing board, but we're currently going through a strategic planning process. As I say, we're ten years old this year and Erin has been leading our strategic planning process and over the last couple of days there's been an opportunity for each of you to actually do the survey which will inform our strategic direction for the next five years. So if you haven't taken that opportunity, there's still the opportunity to do that on-line. But I'll just pass over to Erin to say a few words about the strategic planning.

**Dr Erin Evans:** Thanks, Mark. The other thing that I do in my day-to-day work is work on strategy, because I really love the power of strategy to leverage change and if an organisation should be trying to leverage change there's a lot to be done in the health system and I think that Health Consumers Queensland is the pivotal point of where things should be centred towards. Since being on the board four years ago I've been involved in the development of strategy and I think that that strategic focus has continued to help the organisation in many ways to sort of punch above its weight, to navigate through some of

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the complexities. We've gone from when I was first joined being independent and unfunded. Great to have some independence, but not so great to not have very much money and so the point of the strategy was really to be able to be very focused about what the organisation would or wouldn't do and so we went through quite a long process of really understanding the organisation and the strategy defined how the organisation was navigating through that change until luckily, we became refunded. And you can see in the current version of the strategy there's quite a lot there about consulting the organisation and building up, building the reputation of the organisation and it really reflects the fact that we wanted to establish greater trust and ensure refunding in the organisation, because that is so crucial to be able to do more.

It's a great team and we really need that funding at least as a basis for it to continue. I think some of the present feeling, because the strategy needs to be setting the path in front of us that we walk into in many ways and I think we're seeing that dual role of consumers there and us to be enabling consumers individually or in groups, but also that we do some of the sort of the undercurrent work of the system as well to change the system. We've been doing some thinking ourselves and some thinking internally and the aim is that we take that back out and do consultation, broad consultation and that it will be a very iterative process of strategy development. So please engage with that. We want that strategy to be meaningful and an alive representation, to help show what health consumers doesn't do, as much as what it does do.

**Mark:** So thank you Erin. I'm conscious of the time, which is probably my favourite saying in board meetings, so we're actually going to hand it over to you to ask some questions. But just picking up on the last session, today is actually World Elder Abuse Awareness Day, so please be kind to me. So over to you.

There's a question right at the back. Odetta.

**Audience member:** Thank you, Mark for acknowledging my participation and Janelle and Melissa and I'm sure that we acknowledge the other members, as well. I always believe that we stand on people's shoulder who have done the work before ours and

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tomorrow, others will stand on our shoulders to keep the journey going. In 2008, we wouldn't expect that big progress not only for the HCQ, not only Statewide but at the national level. So my question is, how do you see HCQ in 2025?

**Mark:** I'm going to pass that over to Erin.

**Erin:** Oh, thanks Mark. I think one of the things that I saw in Health Consumers Queensland, to me it was one of the turning points. We were partnered in the clinical Senate and we had the opportunity of consumers up at a clinical Senate meeting telling their stories and I almost felt like it was a house of cards of some of this sort of world view of the clinician or the people in the system as having to be in control of what happens to these consumers' lives starting to get, you know, the thread starting to pull out from it and now I really see that it will be a rebalancing of the roles and much more a true partnership. I think that the people in the system who aren't engaging will be the laggards and the minority and I think that the changes to the system in terms of digital records and also personal medicine will also really contribute and as far as we can put consumers central into that as much as everything else, that will also really help to make sure that consumers have an equal voice at the table and that people really see that value.

**Audience member:** I'm Christine from Mount Isa. Firstly I'd like to say I've been amazed over the last two days how all speakers haven't all told the same story, but in the sharing there's been such unifying strength around the consumer voice. That's been really wonderful. In the previous panel in the previous session someone had asked a similar question, which I'd like to pose to you around going forward, how do we always ensure that the voice of who is missing, so the voice who was silent, how do we continue to draw that out? We've got quite motivated people to participate in consumer networks and we try to target particular people, but we're always going to have pockets of our society whose voice is silent and that we need to do more on. Can you provide one to two points about that?

**Rachelle:** I just chaired the last session or one of them in break-out room one where QuyNH QuiVAA which is for alcohol and drug use support were participating in a consumer engagement process and even just their journey, it's difficult, but once you



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start looking and offering opportunities I think then you start to see people want to take them. They were talking about setting up their steering committee, they had 25 expressions of interest for a committee as they were saying, those consumers are basically breaking the law. So I thought that was a great step forward for society that that was an opportunity. So I think we're definitely not there yet, but I do see the tide starting to turn. I think the standards are a fantastic beginning as well for health services, but they can't do it all alone and it's going to take, it's taking everyone's voice and opportunity to continue, because we can't just rely on leadership. We need to actually work at top down and bottom up to actually help and those groups are difficult to engage in many things, but that shouldn't be an excuse. Because we actually, if we look we will find and if we offer, they will come and I think that's the way we have to go forward.

**Audience member:** Hi, thanks. I'm Steve Williamson chief executive of Central Queensland hospital and health service and I'd make one comment and ask one question. The comment is, I think the conference has been fantastic. That theme of Evolution of Engagement has been really positive and I've learnt a lot, an incredible amount hearing from successes elsewhere. The other part of the comment is I'd like to acknowledge the passionate leadership and the impact of Melissa as your chief executive. That's having a fantastic impact across Queensland Health. It's great to see that and I've seen some of that first-hand. My question is, if you could change one thing in hospital and health services to accelerate that Evolution of Engagement what would it be and how could I help you take that message back to other hospital and health services?

**Panel member:** I have a very immediate answer and it comes to the point of, we talk about co-design. I've been really drawn organically into the concept also of human-centred design. The idea of just being human. It's a comment also on the previous question, we have such a great capacity for technology and advancement and digitalising that we also have to make sure that we ensure that we're humans parallel alongside that. That there's great work being done particularly in the UK around compassionate communities and the public health approach, and actually the social capacity and social capital of us as individuals and particularly as individuals and humans to grow or engage and evolutionise consumer engagement actually comes back to the individual of being

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a human, and having that conversation with the person next to you regardless of whether you are a doctor, nurse, a mother, carer, carpark attendant or the Director-General. And I feel often with so much social media and the instant gratification now that we have and the instant response that we are expecting, but that comes at a distance, you lose that human interaction and so that's a very soft answer to it, but I think we can't lose that in the purpose of Health Consumers Queensland as we advance as an organisation, and as we advance as health consumers and engagers on a social level, as well.

**Audience member:** I'll just add a comment. I chair the community advisory group for Metro North and one of the things we have passionately advocated for is to move away from the complaints and compliments paradigm, because that takes pissed off or passionate people to participate and what about all the middle and all that great goodness that you're getting from everybody that goes through your services and feeding that back to the service deliver Er Dr Lee Bee Wahs. No one goes to work thinking "I'm going to do a bad job today", but inadvertently sometimes they do, so that's my one thing. The second thing particularly highlighted to me at this forum is that we're not there yet and consumers having equal voice at the table, and there's perhaps a bit of tick a box and rubber stamping of "we've met that" and so I guess I would encourage HHSs to train staff in legitimate consumer engagement as well so that when consumers are at the table they feel valued.

**Mark:** Time for two more questions.

**Audience member:** Hello, it's Natasha. So I was outside before and I've come in late, so forgive me if you've answered this in other questions. But I've noticed the zing and the zest bubble and I was just noticed, what is zing and zest and what does it mean to each of you?

**Mark:** So, Steve? The most zingful and zestful person on the board.

**Steve:** I've only been here a short time, three years, but in that time I've seen an increase in outreach to communities in rural and remote areas. There's still a long way to go. A provision of training and resourcing to small organisations, to enable them to

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develop the skills and empower them to take on the role of advocates. On a personal level - I'll go out on a limb here - the areas that I think we can do more and my passion is Indigenous health and a shift from bricks and mortar response to health to primary and preventative health care. I really think that that's something that some systemic change is required. That comes from my being a rural resident and observing what's happening out there. But primarily I think the resourcing and the empowering of individuals. We've certainly seen our membership increase and it's continually increasing. The level of participation in these conferences and the value and the importance of the issues raised and I think they're really large improvements.

**Mark:** So one of the reasons why we included zing and zest as a value was when we were going through that process that the board was very keen not to just come up with standard words that everybody has in their values and so I think if you look at most people's strategic plans and they look at integrity and all those buzz words of the moment. But we felt that zing and zest really reflected what we were about. It's about making sure that as an organisation we're out there, we were agitating in a respectful way, but that also we needed to have some spring in our step, as well. But it wasn't about an organisation that was just consolidating although that was something that we needed to do. But it was actually, in fact, taking the next step forward. In fact, not a step but a real bound forward. So that hopefully answers your question.

**Melissa Fox:** Can I jump in?

**Mark:** And we actually did get some pushback from the staff, I have to say.

**Melissa:** It was the other way round, Mark! Sorry, I just wanted to jump in and say I'm zing, Jo's zest. I actually think - tell me if you agree - this is one of the most important values that guides our work to bring energy and positivity to helping you have an impact so we really appreciate that you chose that.

>>: I think it's interesting, the zing and zest is sometimes when people comment on Health Consumers Queensland and they give us a report or something back they go "And

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I can definitely feel the zing and zest" and it's like, yeah.

>>: A lot of these things were co-designed in terms of the values.

**Mark:** Last question.

**Audience member:** Hello, my name is Jack, I'm a midwife at Ipswich Hospital. Mine is not really a question it's more of a statement. I came across this excellent conference by chance. Until yesterday I had no idea that the Health Consumers Queensland organisation even exists and I doubt many of my colleagues know that either. Over the past two days it's become inherently clear to me the important work done behind the scenes with consumer engagement to make change. I'd like to see more visibility within the HHS of the importance of consumer engagement as a positive way to provide the best clinical care. That's all. (APPLAUSE)

**Mark:** Thank you. Thank you very much for that. That actually raises a point that I meant to make earlier. I think this conference has been really well served by a team of people who've actually been doing the captioning. Sometimes the sound system up here is actually quite difficult to hear the questions, so can I personally on your behalf thank Deane Fallows, Tina Fallows, Sharon Diep, Jason Bradley and Mal Monks who have coped very well with putting the captions up on the screen. I did thank them earlier, but I'll thank them again, because I think they've done an extraordinary job. Melissa and her team, but in particular, Michael. Michael's brought zing and zest to our organisation, I've got to say. But also Chelsea, I think Chelsea this is your third conference that you've done for us and they just keep getting better and better, so thank you Chelsea. And also, Suzanne who I'd like to certainly also point out, as well. Suzanne has been doing some graphics as we've been going through the conference. But rather than actually mentioning everybody by name I'd just like really to thank the very, very hard-working team at Health Consumers Queensland. (APPLAUSE)

So we did promise we'd try to get you out. I have two minutes to say this. We hope that you leave here inspired about The Evolution of Engagement and your role in consumer

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partnerships that have meaningful and impact. Good consumer engagement is best cultivated with patience, trust and respect helping the right partnership to bloom and create the best possible health care system for all. Our annual forum is for you to share learnings, develop networks, to energise yet also to challenge us. We look forward to receiving your feedback from today by the evaluation form in your bag about your experience of our forum and ideas for the future. Please let us know through completing your forms and get back in touch with us. If you've loved it, give us the thumbs up. If you haven't, have a nice weekend anyway. (APPLAUSE).